



Synergizing Epidemiologic Research on Rare Cancers

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Working Groups Report

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Understudied Rare Cancers**


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What is the state of science-what do we know?

- Descriptive data available except rare subtypes**
 - Varies between cancer sites**
 - For some, much of the research from international studies**
 - Differences between racial groups**
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What are the scientific gaps?

- **Biological mechanisms for many cancers**
 - **Molecular sub-classification (head and neck, leukemia, brain)**
 - **Latency period between exposure and effect**
 - **Pre-diagnostic lesions**
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What are the scientific gaps?

- **Predisposing diseases**
- **Lack of susceptibility and early detection markers**
- **Lack of understanding of major biological and physiological processes (energy balance, blood-brain barrier, viral load, immune mechanism, environmental exposure assessment, ...)**

What scientific obstacles impede progress?

- **Lack of better definitions of histological classification**
- **Relatively small sample size achievable by single-site studies**
- **Ultra-rapid case ascertainment**
- **Difficulty in getting appropriate biospecimens**
- **Lack of standardized core questions**

What scientific obstacles impede progress?

- **Data collection costs**
- **HIPAA**
- **Lack of standard bioinformatics and technology integration**
- **Limited collaborations between the different disciplines**
- **Lack of appropriate funding mechanism for interdisciplinary research**

Solutions to these obstacles

- **Targeted \$\$\$\$\$s (RFAs, special review and special study sections)**
- **Educate members of EPIC**
- **Cross training**
- **Coordination of resources**
- **Involvement of advocacy and private organizations**
- **Flexibility of mechanisms of funding to achieve academic credit**

Solutions to these obstacles

- **Build new consortia and coordination, linkages, and communications among existing consortia**
- **Communication and coordination between agencies such as NCI, ACS, and CDC.**
- **Special National Registries of Rare Cancers**
- **Higher funding limits for R03's**
- **Specific plans for junior investigators**



Understudied Rare Cancers Working Groups Summary Report

THANK YOU!